

Autism CARES Act Summary

August 11, 2014

Autism CARES Act (P.L. 113-157)

Detailed Summary of Changes to the Law

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President Barack Obama signed the Autism Collaboration, Accountability, Research, Education, and Support Act of 2014, or Autism CARES Act, into law on August 8, 2014 as Public Law 113-157. This Act reauthorizes the Combating Autism Reauthorization Act of 2011 (originally the Combating Autism Act of 2006) for five years. The House bill (H.R.4631) was introduced on May 9, 2014 by Rep. Chris Smith (R-NJ) and Mike Doyle (D-PA) and passed the House by unanimous consent on June 24, 2014. The Senate bill was introduced on June 9, 2014 by Senators Bob Menendez (D-NJ) and Mike Enzi (R-WY) (S.2449) and passed by unanimous consent on July 31, 2014. These bicameral companion bills had strong bipartisan support in both chambers.



Since it was first enacted in 2006, the law has helped to expand research and coordination at the National Institutes of Health (NIH), increase public awareness and surveillance at the Centers for Disease Control and Prevention (CDC), and expand interdisciplinary health professional training to identify and support children and youth with Autism Spectrum Disorders (ASD) and their families through the Health Resources and Services Administration (HRSA). The Autism CARES Act will renew these efforts and make some important improvements.

Following is a detailed summary of the changes to the law (the underlined are new additions):

The first major change is the renaming of the law to the **Autism Collaboration, Accountability, Research, Education, and Support Act of 2014 or Autism CARES Act** which better reflects what the law does and respects the wishes of advocates, who felt the original title was stigmatizing.

Section 2. National Autism Spectrum Disorder Initiative

The CARES Act requires the U.S. Secretary of Health and Human Services (HHS) to designate an existing official within the department to oversee (in consultation with the Secretaries of Defense and Education) the implementation of activities under the law (taking into account the strategic plan developed by the Interagency Autism Coordinating Committee (IACC)). Currently, the Director of NIMH chairs the IACC, but there is no single individual designated to oversee the entire federal coordination of all agency activities authorized under the law. The CARES Act also requires this individual to ensure the federal autism activities are "not unnecessarily duplicative," a reference to a November 2013 General Accounting Office report that found some activities to have "potential for unnecessary duplication."

Section 3. Research Program

The Combating Autism Act authorized the Centers for Disease Control (CDC) and Prevention to award grants or cooperative agreements for the collection, analysis, and report of state epidemiological data on ASD and other developmental disabilities (DD). The 2006 law also established regional centers of excellence to collect and analyze information on the number, incidence, correlates, and causes of such disabilities.

Section 3 of the CARES Act specifies that the CDC collect and report epidemiological data on both children and adults. It also adds "children and adults" to the activities of the Centers of Excellence. This change reflects advocacy efforts to focus more attention of research activities across the lifespan.

Section 4. Autism Intervention

The Combating Autism Act of 2006 authorized additional federal activities to 1) inform, educate, and increase awareness; 2) promote research into the development and validation of reliable screening tools; 3) promote early screening; and 4) increase the number of individuals trained to confirm or rule out ASD and provide evidence-based interventions. The law also directs the Secretary of HHS to provide culturally competent information regarding ASD and other DD and evidence-based interventions for such individuals and their families. It also requires states to provide individuals with information about state and local resources.

The Combating Autism Act also authorized the Secretary to 1) develop a curriculum for continuing education for professionals to understand and use valid, reliable screening tools; 2) collect, store, coordinate, and make publicly available such tools and products; 3) expand existing interdisciplinary training opportunities and increase the number of sites able to diagnose individuals with ASD/DD (such as Leadership Education in Neurodevelopmental and Related Disabilities or LEND); 4) promote research into tools allowing for earlier diagnoses; and 5) promote research and guidelines for evidence-based interventions.

Section 4 of the CARES Act re-states that the information and education on ASD/DD prepared for the public be "culturally competent."

In addition, the Act urges states to "include respite care for caregivers of individuals with ASD" to the list of available services and supports within its public awareness materials.

The Act also adds that Maternal and Child Health interdisciplinary training programs (such as LEND) demonstrate an ability to use a family-centered approach, which may include collaborating with research centers or networks to provide training for providers of respite care (as defined in section 2901). Respite care is defined in the section 2901 as planned or emergency care provided to a child or adult with a special need in order to provide temporary relief to the family caregiver of that child or adult. Research centers or networks could include University Centers for Excellence in Developmental Disabilities (UCEDD) programs authorized under the DD Act.

The Act changes the wording under grants to develop interventions (under 399 (f) Interventions) to read "'grants or contracts, which may include grants or contracts to research centers or networks, to determine the evidence-based practices for interventions to improve the physical and behavioral health of individuals with ASD and other DD.'

Section 5. Interagency Autism Coordinating Committee

The Combating Autism Act reauthorized the Interagency Autism Coordinating Committee (IACC), originally established under the Children's Health Act. The purpose of the IACC is to coordinate all efforts within the Department of HHS concerning ASD activities; develop and update advances in research; monitor and make recommendations to the Secretary of HHS; make recommendations regarding public input; and develop and update a strategic plan for research to be submitted to Congress.

Section 5 of the CARES Act reauthorizes and amends the IACC by requiring it to monitor the implementation of its strategic plan, including research on supports and services (to the extent practicable), and by providing recommendations to ensure federal research activities are not unnecessarily duplicative.

The Act also changes the statutory membership of the IACC. First, it adds additional federal members to include the Administration for Community Living, Administration for Children and Families, the Food and Drug Administration, Centers for Medicare and Medicaid Services (CMS), the Health Resources and Services Administration, as well as representatives of the Departments of Defense and Education.

The Act also allows additional non-federal members: at least two (rather than one) individuals on the autism spectrum, at least two (rather than one) parents or legal guardians of individuals on the autism spectrum, and at least two (rather than one) representatives of leading research, service, and advocacy organizations. Non-federal members now make up "not more than 1/2 of the total membership," up from 1/3 total.

Section 6. Reports

Sec. 6 of the Act adds an additional report to Congress and changes some of the required content (of existing reports to Congress). A progress report is required 4 years after enactment (in 2018). This report must now include information on the incidence and prevalence of autism spectrum disorder, including prevalence among children and adults, and identification of any changes over time. Report now requires that information about average age of diagnosis and treatment include how that varies by population subgroups and severity level as practicable. Information about the effectiveness of interventions must now include how the age of the child or other factors, such as demographic characteristics, may affect such effectiveness.

Report on Young Adults and Transitioning Youth

Due to the strong interest of the House and Senate champions of the bill, the law now requires a new Congressional report devoted to the challenges of youth transitioning from school to adult services, education, and employment opportunities. For this report, the U.S. Secretary of HHS must coordinate with the secretaries of Education, Transportation, Labor, and Housing and Urban Development. The report must be delivered to the Senate HELP and House Energy and Commerce Committees not later than two years following enactment of the CARES Act (August 8, 2016).

The new transition report must contain (from the text of the law):

- (A) demographic characteristics of youth transitioning from school-based to community-based supports;
- (B) an overview of policies and programs relevant to young adults with autism spectrum disorder relating to post-secondary school transitional services, including an identification of existing Federal laws, regulations, policies, research, and programs;
- (C) proposals on establishing best practices guidelines to ensure
 - (i) interdisciplinary coordination between all relevant service providers receiving Federal funding;
 - (ii) coordination with transitioning youth and the family of such transitioning youth; and
 - (iii) inclusion of the individualized education program for the transitioning youth, as prescribed in section 614 of the Individuals with Disabilities Education Act of 2004 (20 U.S.C. 1414);
- (D) comprehensive approaches to transitioning from existing school-based services to services available during adulthood, including-
 - (i) services that increase access to, and improve integration and completion of, post-secondary education, peer support, vocational training (as defined in section 103 of the Rehabilitation Act of 1973 (29 U.S.C.723), rehabilitation, self-advocacy skills, and competitive, integrated employment;
 - (ii) community-based behavioral supports and interventions;
 - (iii) community-based integrated residential services, housing, and transportation
 - (iv) nutrition, health and wellness, recreational, and social activities;
 - (v) personal safety services for individuals with autism spectrum disorder related to public safety agencies or the criminal justice system; and
 - (vi) evidence-based approaches for coordination of resources and services once individuals have aged out of post-secondary education; and
- (E) proposals that seek to improve outcomes for adults with autism spectrum disorder making the transition from a school-based support system to adulthood by-
 - (i) increasing the effectiveness of programs that provide transition services;
 - (ii) increasing the ability of the relevant service providers described in sub paragraph (C) to provide supports and services to underserved populations and region

(iii) increasing the efficiency of service delivery to maximize resources and outcomes, including with respect to the integration of and collaboration among services for transitioning youth;

(iv) ensuring access to all services necessary to transitioning youth of all capabilities; and

(v) encouraging transitioning youth to utilize all available transition services to maximize independence, equal opportunity, full participation, and self-sufficiency.

Section 7. Authorization of Appropriations

The Act authorizes level funding (at approximately FY 2010 levels) except for funding for the National Institutes of Health. The authorization for appropriations for NIH is raised from \$161 million to \$190 million to (according to congressional staff) reflect the actual current spending on autism activities at the institutes.

According the Congressional Budget Office (CBO), the CARES Act reauthorizes funding for activities under the law at a level of \$260 million per year or \$1.3 billion over the five year authorization period (2015-2019). According to CBO the amounts are targeted in the following way:

- \$22 million annually (\$90 million over five years) for the developmental disabilities surveillance and research program at the CDC;
- \$48 million annually (\$240 million over five years) for HRSA autism education, early detection, and intervention, and;
- \$190 million annually (\$950 million over five years) for research grants at the National Institutes of Health (NIH) and the operations of the Interagency Autism Coordinating Committee (IACC).

For more information about the Autism CARES Act, including the full text of the law, please see [AUCD's public policy page](#). For information about technical assistance provided to LEND and Developmental-Behavioral Pediatrics (DBP) programs, see [AUCD's Interdisciplinary Technical Assistance Center on Autism and Developmental Disabilities](#). For more information about AUCD and its member programs, see www.AUCD.org.